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The meaning of acceptance and body awareness for individuals living with long-term pain – implications for rehabilitation

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The meaning of acceptance and body awareness for individuals living with long-term pain – implications for rehabilitation

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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Life can only be understood backwards,
but it must be lived forwards.

Søren Kierkegaard

To all people who struggle with pain.

ABSTRACT

Background: Chronic or long-term pain, usually defined as pain lasting at least three to six months, is generally understood as a multidimensional phenomenon, often requiring a multidisciplinary rehabilitation approach. The aetiology of long-term musculoskeletal pain is considered to be multi-factorial. Although body awareness treatment approaches and acceptance-based methods are incorporated in pain rehabilitation, there is still a need for knowledge as to how they contribute to the process of change in rehabilitation. Both body awareness and acceptance are multi-dimensional concept.

Aims: The aims of the thesis were to describe how individuals with long-term musculoskeletal pain experience and relate to (a) their aching body (Study I), (b) body awareness as a resource in rehabilitation (Study II). A further aim was to investigate how individuals participating in a multi-professional rehabilitation programme experience and understand (c) the meaning of acceptance when entering the rehabilitation programme (Study III) and (d) how this meaning change during the rehabilitation programme (Study IV).

Methods and results: Three different samples were included, in total 27 women and 12 men between the ages of 24–72 years with pain duration between 2.5–35 years. In-depth interviews and a phenomenological research approach were chosen as well as a qualitative longitudinal research design.

In **study I,** the results indicate that patients with long-term pain can be found along a spectrum from accepting to rejecting the aching body. Body awareness and a trust in ones' body seem to be important on the path towards acceptance of the body as well as one's life situation as whole.

In **study II,** three constituents were identified as a gradual 'moving forward' process, which was characterized by a shift in attentional focus that concerns the lived body, the embodied self and the life-world beyond the experience of pain.

In **study III,** the findings were that patients can hold different understandings of acceptance when entering a rehabilitation program expressed as; *the only way forward, a possible but challenging way forward* and *no way forward.*

In **study IV,** four meaning structures that deepened the understanding of acceptance as well as illustrating key aspects of an embodied learning process during rehabilitation could be described; *acceptance as liberation*, *acceptance as acknowledging the need for change*, *acceptance as tolerating ambivalence* and *acceptance as failure*. Bodily-existential challenges were highlighted as well as the importance of social support.

Conclusions: This thesis has shown both the importance of acceptance for rehabilitation as well as the role of embodied transformative learning. Acceptance was found to be a multifaceted phenomenon varying from person to person and over time. Although body awareness approaches are prevalent in some clinical settings, these studies show from an experiential perspective that body awareness has an important role to play in the successful rehabilitation of long-term pain. The findings in this thesis support the person-centred approach in rehabilitation, weather in group or individual treatment.

SAMMANFATTNING

Bakgrund: Kronisk eller långvarig smärta, vanligtvis definierad som smärta som varat minst tre till sex månader, förstås generellt som ett flerdimensionellt fenomen, vilket ofta kräver en multidisciplinär rehabiliteringsinsats. Etiologin vid långvarig muskuloskeletal smärta är multifaktoriell. Även om kroppsmedvetenhet och acceptans-baserade metoder ingår i smärtrehabilitering, saknas det idag kunskap om hur de bidrar till förändringsprocessen i rehabilitering. Både kroppsmedvetenhet och acceptans är multidimensionella begrepp.

Mål: Avhandlingens syfte var att beskriva hur individer med långvarig muskuloskeletal smärta upplever (a) sin värkande kropp (Studie I) och (b) kroppsmedvetenhet som en resurs i rehabilitering (Studie II). Ett annat syfte var att undersöka hur individer som deltar i ett multiprofessionellt rehabiliteringsprogram upplever och förstår c) mening/innebörd av acceptans då de påbörjar rehabiliteringsprogrammet (Studie III) och d) hur denna mening/innebörd förändras under rehabiliteringsprogrammet (Studie IV).

Metoder och resultat: Tre olika urval inkluderades, totalt 27 kvinnor och 12 män mellan 24-72 år med smärtduration mellan 2,5-35 år. Djupintervjuer och en fenomenologisk forskningsansats valdes liksom en kvalitativ longitudinell forskningsdesign.

I **studie I** indikerar resultaten att patienter med långvarig smärta kan befinna sig längs ett kontinuum från att acceptera till att ta avstånd från den värkande kroppen. Kroppsmedvetenhet och en tillit till kroppen tycks vara viktigt på vägen mot att kunna acceptera kroppen såväl som livssituation som helhet.

I **studien II** identifierades tre konstituenter som beskriver en gradvis ”framåtriktad rörelse” som kännetecknas av ett förändrat uppmärksamhetsfält som berör den levda kroppen, det förkroppsligade självet och livsvärlden bortom upplevelsen av smärtan.

I **studie III** framkom att patienter med långvarig smärta kan ha olika uppfattningar om acceptans då de påbörjar ett rehabiliteringsprogram, uttryckt som; *det enda sättet framåt, en möjlig men utmanande väg framåt* och *ingen väg framåt.*

I **studie IV** beskrevs fyra meningsstrukturer som fördjupar förståelsen för acceptans samt illustrerar viktiga aspekter av den förkroppsligade lärandeprocessen under rehabilitering; *acceptans som befrielse, acceptans som ett erkännanande av behovet av förändring, acceptans som tolerans av ambivalens* och *acceptans som misslyckande*. Kroppsliga-existentiella utmaningar lyftes fram samt vikten av socialt stöd.

Slutsatser: Denna avhandling har visat såväl på vikten av acceptans för rehabilitering som betydelsen av ett förkroppsligat transformativt lärande. Acceptans visade sig vara ett mångfacetterat fenomen som varierar från person till person och över tid. Även om kroppsmedvetenhetsmetoder är vanliga i vissa kliniska miljöer visar dessa studier ur ett upplevelse-/erfarenhetsperspektiv att kroppsmedvetenhet är betydelsefullt för en framgångsrik rehabilitering av långvarig smärta. Resultaten i denna avhandling stöder det personcentrerade arbetssättet vid rehabilitering, oavsett om behandlingen sker i grupp eller individuellt.

LIST OF SCIENTIFIC PAPERS

I. Afrell M, Biguet G, Rudebeck CE. Living with a body in pain – between acceptance and denial. *Scandinavian Journal of Caring Sciences*, 2007;21:291–296.

II. Biguet G, Levy Berg A, Bullington J, Nilsson-Wikmar L. Body awareness as a resource in the context of long-term pain. A phenomenological description from the patients' perspective. *Submitted.*

III. Biguet G, Nilsson-Wikmar L, Bullington J, Flink B, Löfgren M. Meanings of 'acceptance' for patients with long-term pain when starting rehabilitation. *Disability and Rehabilitation*, 2016;38(13):1257–1267.

IV. Biguet G, Löfgren M, Nilsson-Wikmar L, Bullington J. The meaning and process of acceptance for patients with long-term pain when participating in rehabilitation: a longitudinal study. *Manuscript in preparation.*

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Study II and IV. This may not be the final version before publication.

LIST OF ABBREVIATIONS

ACT	Acceptance & Commitment Therapy
BBAT	Basic Body Awareness Therapy
CBT	Cognitive and Behavioural Therapy
CPAQ	Chronic Pain Acceptance Questionnaire
EPP	Empirical Phenomenological Psychological method
IASP	International Association for the Study of Pain
IPA	Interpretative Phenomenological Analysis
SBU	The Swedish Council on Health Technology Assessment
WHO	World Health Organization

DEFINITIONS AND CONCEPTS

In this thesis the term **“long-term pain”** were used, even though one finds the term “chronic pain” in the literature. We have decided on this term because, first and foremost, it was the way in which the participants in the studies referred to their situation. Furthermore, the term long-term pain is more often used in patient information, maybe because of the risk that the term chronic is attributed with negative meaning. We stipulate that the terms long-standing pain, as well as long-term or long-lasting pain, are identical to what is referred to as chronic pain.

PREFACE

Long-term pain changes the landscape of a person's world. What does that mean? The experience of pain is essentially an individual personal experience, therefore living with and managing pain can mean so many things.

My clinical experiences as a physiotherapist (although several years ago) has provided me with an insight into the fact that some patients reach acceptance while others find that the limitations in their daily life make it difficult as they understand that there is no cure to free them from their pain. Others grow as a person.

Body awareness is a fascinating area in my profession and the transformations it generates leave me amazed and puzzled at the same time: what happens? What is the underlying process we are facilitating? How is it that many individuals with long-term pain respond well to it while others do not? What does it mean to practice body awareness when you have long-term pain? Is there a meaning at all?

So many questions started this journey and all the work behind this thesis that has been one of the most learning experiences I have had. I not only learned, I have been surprised about so many things! About the knowledge and wisdom of patients, about discovering powerful processes. I did not know that we could in physiotherapy, foster such things as pain acceptance as a mean of moving forward in life, even in the presence of pain.

These and many new phenomena were brought into light and new knowledge emerged. However, I know, this is just the start of a new path through a whole new field to explore. We have some answers and many new interesting clinical questions to keep investigating, and I am looking forward to that next trip!

CONTENTS

1 BACKGROUND

1.1 Understanding long-term pain

1.1.1 What is pain?

According to the International Association for the Study of Pain (IASP) pain is defined as "*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage"* (Merskey & Bogduk, 1994). This definition takes into account the physical nature of pain as well as psychological processes and pain as a subjective experience.

Pain is a universal human experience and almost everyone has experienced pain. For the majority, the experience of pains lasts for a relatively short period. When pain lasts longer than three to six months beyond the expected time for healing, it is defined as "chronic" (Merskey & Bogduk, 1994), i.e. it is persistent, either continuous or recurrent, and factors other than physiological processes have an impact on functioning, role participation and overall quality of life (Lambert, 2010).

1.1.2 What is long-term pain?

Long-term pain cannot be understood by generalizing from an understanding of acute pain, which functions as an important alarm system of the body necessary for survival. When pain becomes long-term, it does not serve the same protective function as acute pain. As response processes continue and the pain urges us to take action, it often becomes a central focus of a person's existence, even though it does not serve a protective function. The degree of attention paid to the pain, personal beliefs about the nature of pain and meanings given to bodily experiences can have an important impact on the experience of pain.

Although localization, aetiology and the diagnosis differ, long-term pain itself is considered as a disease in its own right, rather than solely as a symptom of an underlying disease (Taylor et al., 2015). Recently, a changed definition of chronic pain has been suggested, as the time-related definition of long-term pain does not take into account the multi-dimensional nature of pain and prognostic factors responsible for continued pain. Many other factors than pain duration can have an impact on the development and maintenance of long-term pain, and are thus important for guiding the treatment of long-term pain (Pergolizzi et al., 2012).

1.1.3 The prevalence of long-term pain

Long-term pain is common and the economic burden for the individual and for society is high. One of five persons in Europe experiences long-term pain of moderate to severe intensity (Breivik, Collett, Ventafridda, Cohen, & Gallacher,

2006; Leadley, Armstrong, Lee, Allen, & Kleijnen, 2012), in some studies, up to 40 % of the general population are estimated to have long-term pain (Fayaz, Croft, Langford, Donaldson, & Jones, 2016). Women are more likely than men to report long-term pain as well as persons in later life (Breivik et al., 2006; Tsang et al., 2008; Wijnhoven, de Vet, & Picavet, 2006) As in other European countries, significantly intense long-term pain is one of the most prevalent and costly health conditions in Sweden with a prevalence of approximately 20 % of the general population (Breivik et al., 2006; The Swedish Council on Health Technology Assessment, 2010). Musculoskeletal pain is considered to be the most prominent long-term pain condition, such e.g. generalized widespread pain, fibromyalgia, osteoarthritis as well as non-specific neck-shoulder and low back pain (Gerdle, Bjork, Henriksson, & Bengtsson, 2004). This is, like other long-term health conditions, a growing phenomenon worldwide, considered by the World Health Organization (WHO) to be a global health problem (IASP). Despite comprehensive research, it is still among the least well understood phenomena in medicine (Gatchel, Peng, Peters, Fuchs, & Turk, 2007).

1.1.4 The aetiology of long-term pain

The aetiology for the development and maintenance of long-term pain is only partly understood, but it is acknowledged to be multifactorial. Research is ongoing to further understand underlying mechanisms, such as the connections between neurobiological preconditions and changes in the central nerve system, genetic vulnerability, and psychological and sociocultural factors (Gatchel et al., 2007). It is known that pain can be triggered, maintained or exacerbated by psychological factors, such as fear-avoidance, catastrophizing and hypervigilance which can play a role when pain becomes sustained, e.g. according to behavioural reactions such as avoidance of activity, a helpful strategy in acute pain but maladaptive in long-term pain (Vlaeyen & Linton, 2012). Emotional reactions and distress such as depression and anxiety as well as anger and experiencing pain as a threat can influence the pain, as well as social consequences and reactions from the environment (Gatchel et al., 2007; Linton & Bergbom, 2011; Morley, 2008).

1.1.5 The impact of long-term pain

Besides the pain itself, individuals with long-term pain report a major impact on their life, in particular on physical function, health-related quality of life, psychological wellbeing and social relationships and work ability (Andersen et al., 2014; Turk, Dworkin, et al., 2008) Although consequences may vary considerably between individuals, suffering is often pervasive (Andersen et al., 2014).

Many individuals with long-term pain suffer also from co-occurring psychiatric problems, most common are high level of depression and anxiety (Andersen et al.,

2014; Burke, Mathias, & Denson, 2015; Miller & Cano, 2009; Turk, Dworkin, et al., 2008). The relationship between long-term pain and psychiatric comorbidity is complex and is not fully understood. However it is recognized that individuals with long-term pain are at increased risk of developing psychiatric problems compared to the general population (Gerhardt et al., 2011; Miller & Cano, 2009).

Burke et al (2015) confirmed that people with long-term pain are more likely to experience emotional distress in a physical way, i.e. the physical aspects of the overall experience rather than other psychological problems related to long-term pain. When planning interventions and rehabilitation, anxiously heightened attention towards bodily sensation should be therapeutically identified and addressed in rehabilitation.

1.1.6 The patients' experience of long-term pain

Numerous qualitative studies concern the experience of what it is like to live with long-term pain and how it impacts on individuals' life. Reviews, syntheses and meta syntheses can be found in diagnosis related groups i.e. such as low back pain (Bunzli, Watkins, Smith, Schutze, & O'Sullivan, 2013; Froud et al., 2014; MacNeela, Doyle, O'Gorman, Ruane, & McGuire, 2015; Snelgrove & Liossi, 2013), fibromyalgia (Sim & Madden, 2008) and in long-term musculoskeletal pain conditions (Crowe et al., 2017; Löfgren, Schüldt Ekholm, Schult, & Ekholm, 2016; Osborn & Rodham, 2010; Toye et al., 2013; Toye, Seers, Hannink, & Barker, 2017).

According to the literature above, there are several areas of concern for individuals with long-term pain; such as the struggle to prove legitimacy due to the "invisibility" of the pain, a disrupted sense of self and identity, altered sense of the body, lack of acceptable explanation for suffering, loss of social roles and relationships, and disrupted biographical trajectory with experiences of an unpredictable present and uncertain future. These concerns highlight the constant struggle that pervades multiple levels in an individual's life.

As pain exacerbates, daily activities become limited. Day-to-day unpredictability creates a timeless present where pain dominates. Spontaneity is lost. The unpredictability is hard to anticipate, which makes it difficult to adapt to it.

The sense of self and identity is severely affected and alienation from the body, the self and thus the life-world are common. Threat to the core sense of a coherent and valuable self is often more threatening than the limitations of daily activities. Individuals also struggle with the limitations of their body and the fundamentally altered relationship between the body and the self. Once familiar and predicable, the body becomes an obstacle and a burden, to that extent that it may well be regarded as a treacherous "it" (Raheim & Haland, 2006). Furthermore, the body

becomes the object of attention rather the object through which experiences and actions in the world are possible (Miles, Curran, Pearce, & Allan, 2005). Bodily experiences are often overwhelming and dominating. Managing the limitations related to the body and activities in daily life as well as problems related to identity are often seen as worse problems than the pain per se.

1.2 Treatment and pain rehabilitation

1.2.1 The biopsychosocial model

The complexity of long-term pain suggests multiple treatment approaches are needed to facilitate pain management and pain rehabilitation in primary health care as well as in specialized pain rehabilitation practice (Breivik, Eisenberg, & O'Brien, 2013; O'Sullivan, 2012; Turk, Swanson, & Tunks, 2008). The biopsychosocial model already developed in 1970s (Engel, 1977) is generally acknowledged as a viable approach and predominates in the treatment of long-term pain (Cheatle, 2016; Gatchel et al., 2007; Nicholas, 2008). In clinical practice this means that individuals with long-term pain have to be considered in all dimensions and treatment has to be adapted accordingly, otherwise the overall effectiveness of treatment will be poor (Cheatle, 2016; Nicholas, 2008). To take into account that a human being is both biological, psychological, social means that one should always consider a human being in all dimensions, including existential aspects, i.e. lived experiences of one's body, sense of self and whole life-world (Bullington, 2009; Svenaeus, 2000, 2015). This is in line with Lima, Alves and Turato (2014) and Carel (2011) who advocate a phenomenological existential approach within pain rehabilitation.

1.2.2 Pain care organization in Sweden

In Sweden primary health care is the first option for individuals with long-term pain. Individuals with disabling long-term pain, i.e. patients on sick leave or at risk for sick leave, who experience major interference in daily life can be referred for specialized care at pain clinics or multidisciplinary rehabilitation units. To some extent, multidisciplinary rehabilitation can also be offered in primary health care for people with less complex pain conditions (The Swedish Council on Health Technology Assessment, 2010).

1.2.3 Multidisciplinary pain rehabilitation

In multidisciplinary rehabilitation, psychological approaches, are common, often consisting of cognitive behavioural therapy (CBT), delivered in group setting, including physical activity/exercise, education, coping skills, and occupational therapy, performed by a professional team consisting of physicians, psychologists, physiotherapists, occupational therapists, social workers and nurses. The

team interacts actively with the patients in goal-setting and reaching the goal (Gatchel, McGeary, McGeary, & Lippe, 2014). The overall goal in rehabilitation is pain reduction, if possible, accompanied by improvements in physical function, improvement of emotional distress and quality of life and return to work (Scascighini, Toma, Dober-Spielmann, & Sprott, 2008; Williams, Eccleston, & Morley, 2012) as well as self-management, i.e. taking care for oneself as effectively as possible (Nicholas, 2008).

1.2.4 The evidence for multidisciplinary pain rehabilitation

The evidence for multidisciplinary rehabilitation has been established, but the outcomes reported are at best moderate, frequently attributed to the large individual differences in treatment outcomes (Kamper et al., 2015; Scascighini et al., 2008; Williams et al., 2012). Clinically relevant effects on sick leave and return to work are reported (Kamper et al., 2015; Norlund, Ropponen, & Alexanderson, 2009) as well as strong evidence for the importance of physical activity and exercise, especially an approach including patient education/information (Macfarlane et al., 2017). However, little is known about which components are beneficial and in what combinations and for whom? (McCracken & Morley, 2014; Williams et al., 2012). To further improve multidisciplinary pain rehabilitation, researchers calls for studies identifying the therapeutic processes that underlie change and treatment outcomes as well as characteristics that can predict improvements in these therapeutic processes (McCracken & Morley, 2014; Morley & Williams, 2015; Williams et al., 2012) The importance of understanding emotional responses in relation to the meaning of pain for each individual has to be emphasized (Morley & Williams, 2015).

1.3 Body awareness and acceptance

1.3.1 Body awareness based approaches

Body awareness treatment approaches are often incorporated in multidisciplinary rehabilitation. Body awareness also referred to 'interoceptive or perceptual awareness', meaning attentional focus on internal bodily signals and evaluative processes (Mehling et al., 2009; Mehling et al., 2011). It includes motor behaviours as well as self-exploration with the goal of learning new movement habits. Enhanced body awareness increases the awareness of the self, and opens up for new ways of acting and interacting with others (Bravo, Skjaerven, Guitard Sein-Echaluce, & Catalan-Matamoros, 2018; Gyllensten, Skar, Miller, & Gard, 2010; Skjaerven et al., 2019). This makes the practice relevant in the context of long-term pain (Mehling et al., 2013; Price & Mehling, 2016; van der Maas et al., 2016) but also challenging, as being attentive to the body in pain and to oneself can be challenging for the individual with long-term pain.

In Scandinavia this treatment approach is formalized as Basic Body Awareness Therapy (BBAT), a movement-based physiotherapeutic method developed in Sweden which gradually expanded among pysiotherapists in Northern Europe. BBAT aims at enhanced body awareness and quality of movement as well as fostering a non-judgemental and compassionate attitude towards the body (Skjaerven et al., 2019). BBAT shows promising effects in several areas such as long-term musculoskeletal pain (Anderson, Strand, & Raheim, 2007; Bravo et al., 2018; Gustafsson, Ekholm, & Ohman, 2004). Even the Norwegian psychomotor physiotherapy, belonging to the body-mind or body awareness therapies in Scandinavia, has recently shown significant results on health rated quality of life and improvement in pain and self-esteem (Bergland, Olsen, & Ekerholt, 2018). However, further studies are called for, including studies exploring how body awareness can contribute to process of change and positive rehabilitation outcomes for long-term pain (Courtois, Cools, & Calsius, 2015; van der Maas et al., 2016).

1.3.2 Acceptance-based approaches

Among the acceptance-based therapeutic approaches, the most well-known is acceptance and commitment therapy (ACT) which is becoming increasingly implemented within pain rehabilitation (McCracken & Morley, 2014). It focuses on adaptive ways of relating to ones' pain when conventional treatments fail to relieve the symptoms, and targets function in order to build up the capacity and stamina to live a meaningful and vital life, even in the presence of pain (McCracken & Vowles, 2014). ACT helps individuals to shift focus from struggling to control the pain, to be able to relate to it in a more flexible manner, leading to increased activity and physical functioning, decreased depression, anxiety and general distress in turn improving their wellbeing and life satisfaction (Hughes, Clark, Colclough, Dale, & McMillan, 2017).

Pain acceptance is one of ACT's therapeutic processes. It is measured by the Chronic Pain Acceptance Questionnaire (CPAQ), composed by two behaviours (and sub-scales): "pain willingness" and "activity engagement". Pain willingness is described as a mental openness towards the idea that pain is part of life and being able to find ways to actively adapt and keep doing things in life without the need to first control this pain. Activity engagement, on the other hand, is described as the capacity to keep physical and social commitment to participating in important activities, making life meaningful (McCracken, Vowles, & Eccleston, 2004). Pain acceptance, as therapeutic process, is a strong mediator for treatment outcomes (McCracken & Gutierrez-Martinez, 2011; Thompson & McCracken, 2011) as well as in other treatment approaches when acceptance is not specifically targeted, e.g. in CBT (Akerblom, Perrin, Rivano Fischer, & McCracken, 2015).

1.3.3 Acceptance as multifaceted concept

Acceptance is a multifaceted concept that can be understood in various ways. There is a risk that the notion of acceptance could be oversimplified or misunderstood, especially in relation to long-term pain (McCracken & Thompson, 2011). Primarily acceptance is a personal and individualized process with varying degrees of resistance to or readiness for acceptance. Existing knowledge base would be enriched by an in-depth understanding of acceptance (Nicholas, 2008).

1.4 Thesis rationale

Long-term pain is a complex and multifaceted condition with limited possibilities for a cure. Comprehensive multidisciplinary rehabilitation is advised and found beneficial with profound results for some, while for others it does not work. Pain rehabilitation has to be further developed and more knowledge is needed about therapeutic processes during rehabilitation. Further, patients should have an active role in rehabilitation while the health care professional's role is to motivate and guide and support active participation in their rehabilitation. To understand the patient perspective is important in order to guide another person.

ACT has a focus on pain acceptance as one of several therapeutic processes. Pain acceptance as an important predictor and mediator for positive treatment outcomes has been demonstrated. However there may be more to accepting pain which should be further investigated. Diverse ways on how acceptance can be achieved are assumed but not fully understood.

There is a limited base of knowledge about how to attain acceptance, especially how to accept the body in pain, and how to integrate long-term pain within one's everyday living. Today, we do not know how an accepting approach to their body and their life situation can be achieved for individuals with long-term pain. We also do not know which intrinsic resources the individual needs to draw upon in order to work towards acceptance and how these processes are affected during rehabilitation. Patients' own experiences are the basis for a sensitive, person-centred approach in health care that takes into account the wider social context of people lives as well as the medical aspects. The purpose of the thesis is to deepen the knowledge of the existential dimensions of living with long-term pain. This includes a life-world perspective with focus on the painful body as lived experience in those struggling with long-term pain.

1.5 Aim of the thesis

The overall aim of this thesis was to obtain a more profound understanding of the experiences and meaning of acceptance for individuals with long-term pain, and to investigate how acceptance can be achieved during rehabilitation, with special focus on the experience of the body and sense of self. A further aim was to explore experiences of body awareness as a resource in rehabilitation, from a first-person perspective. The results of the thesis aimed at to contribute valuable knowledge which can be further developed in interventions resulting in positive outcomes for patients in pain rehabilitation.

More specifically, the aims of the projects were:

1. To explore and describe how individuals with long-term musculoskeletal pain experience and relate to their aching body. (Study I)
2. To investigate how individuals with long-term musculoskeletal pain experience and understand body awareness as a resource in rehabilitation. (Study II)
3. To elucidate the meaning of acceptance in relation to the lived body and sense of self when entering a pain rehabilitation programme. (Study III)
4. To elucidate the meaning of acceptance and the process of change during a 16-week-long multi-professional pain rehabilitation programme. (Study IV)

2 METHODS

2.1 Design

The thesis consists of two parts. The first part investigates lived experiences of the aching body (study I) and body awareness as a resource in rehabilitation (study II). The second part (Study III and IV) concerns the meaning of acceptance and the process of change during rehabilitation. The main interest here was to explore a first-person perspective, considering each individual as a unique person.

All studies are based on individual interviews and a phenomenological research approach. In study I and II, the Empirical Psychological Phenomenological (EPP) method was chosen. Study III and IV are based on a qualitative longitudinal study approach with serial interviews with each participant at the beginning, in the middle and at the end of the rehabilitation programme. The Interpretative Phenomenological Analysis (IPA) method was chosen for data analysis in these studies. An overview of the research design of the studies is given in Table 1.

Table 1. Overview of the research design in studies I–IV

Study	Design	Participants	Data collection	Data analysis
I	Qualitative descriptive design	20 participants (13 women/7 men)	Individual interviews	Empirical phenomenological psychological method (EPP-method)
II	Qualitative descriptive design	10 participants (8 women/2 men)	Individual interviews	Empirical phenomenological psychological method (EPP-method)
III and IV	Qualitative longitudinal research (QLR)	9 participants (6 women/3 men)	3 individual inter-views with each participant during rehabilitation	Interpretative phenomenological analysis (IPA) method

2.2 Study participants and setting

2.2.1 Study participants

Three different samples were studied, in total 39 participants (27 women, 12 men) recruited either from primary health care, specialized pain clinics or outpatient multi-professional pain rehabilitation units. The participants were aged between 24–72 years. All participants spoke Swedish fluently. Their diagnosis differed; such as widespread musculoskeletal pain, fibromyalgia, osteoarthritis, shoulder and cervical strain, long-standing musculoskeletal pain, whiplash related syndrome and tension headache. More than half of the participants were on sick leave (25%–100%). All participants fulfilled the inclusion criterion for long-term pain, i.e. pain for at least three month. Participants' characteristics see Table 2.

In **Study I** a total of 20 participants were recruited from different physiotherapy units in primary health care, a specialized pain clinic and an outpatient multidisciplinary rehabilitation clinic. The inclusion criteria were musculoskeletal pain for more than 3month, participation in physiotherapy treatment due to long-standing musculoskeletal pain, either the patient's own initiative or upon referral. Individuals who had pain because of malignancy were excluded. Fifteen of the participants were born in Sweden. Eight were on sick leave (100%), six (50% and one (75%). Two participants were retired. Most of them had physically demanding jobs such as assistant nurse, unskilled labor and cleaner.

In **Study II** ten participants were recruited from three physiotherapy units in primary health care, one pain clinic at hospital, and one out-patient multi-professional rehabilitation clinic. The inclusion criteria were musculoskeletal pain for more than 3 months, participation in physiotherapy including some kind of body awareness therapy, and willingness to reflect on bodily awareness in relation to the experiences of living with long-term pain in everyday life.

In **Study III and IV** nine participants were recruited from a specialist outpatient pain rehabilitation unit taking part in a 16-week-long multi-professional pain rehabilitation programme. The inclusion criteria were participation in the entire rehabilitation programme and an interest in discussing and reflecting on the meaning of living with and managing persistent pain and how these experiences changed during rehabilitation. Participants who had joined an acceptance and commitment therapy (ACT) treatment programme were excluded. Seven of the nine participants were born in Sweden. The participants' work varied widely; e.g. within education, health care, restaurant and transport service. Three were full-time or half-time students at a university.

Table 2. Characteristics of the participants in study I–IV

Study	Women/men (n)	Age (years)	Recruited from	Diagnosis
I	13/7	30–72 (Md 50.5)	Primary health care, pain clinic or multi-professional rehabilitation unit	Long-standing* musculoskeletal pain and tension (n=20)
II	8/2	25–58 (Md 46)	Primary health care, pain clinic or multi-professional rehabilitation unit	Widespread pain (=5) Fibromyalgia (n=3) Whiplash related syndrome (n=1) Tension headache (=1)
III and IV	6/3	24–52 (Md 46)	16-week-long multi-professional rehabilitation programme	Widespread musculoskeletal pain (=3) Fibromyalgia (n=3) Osteoarthritis, shoulder and cervical strain (n=3)

* long-standing pain = long-term pain

2.2.2 Multi-professional rehabilitation programme

In **Study III and IV** the participants attended a group-based 16-week-long multi-professional rehabilitation programme. The inclusion criteria for this programme were (i) disabling chronic pain (on sick leave or experiencing major interference in daily life due to chronic pain); (ii) age between 18-65 years; (iii) no further medical investigations required. Exclusion criteria were: (i) ongoing major somatic or psychiatric disease; (ii) a history of significant substance abuse; (iii) state of acute crisis. The programme followed evidence-based treatment principles consisting of cognitive behavioural therapy, physical exercise, body awareness therapy, mindfulness meditation, pain management as well as ergonomic and occupational training such as pacing and personal goal-setting. All participants completed the pain rehabilitation programme. Three participants took part in the rehabilitation programme for young adults which had a similar content.

2.3 Data collection

2.3.1 Interviews

In **Study I** individual semi-structured interviews were carried out using an interview guide inspired by the "key questions" method developed by Malterud (1994). This means exploring the individual's view of the problem and thereby acknowledging their competence and own reflections and understandings. Focus in the interviews

was on the participants' perception of and access to their body and bodily experiences in relation the impact of the pain condition on everyday life and how to cope with it. The questions were open-ended to encourage accounts of the participants' life-world experiences. The interviews were conducted by an experienced clinical physiotherapist (MA), lasting approximately 45–75 minutes.

In **Study II** individual semi-structured interviews were carried out with a focus on bodily experiences and how body awareness could be a resource in the participants' rehabilitation and in daily life. Focus was also on how body awareness was addressed in physiotherapy and/or in the rehabilitation programme as well as how the process of getting access to and practicing body awareness developed over time. Efforts were made to focus on body awareness as an overall phenomenon and not only on the experience of the body awareness intervention in the programme. Efforts were also made to get detailed descriptions of the participants' life-world in a spontaneous and non-directed way. The interviews took place at the physiotherapy clinic in a conveniently located room (n=8), the interviewer's workplace (n=1) or the participant's home (n=1) and lasted between 30 and 75 minutes. Before the interviews, two pilot interviews were carried out in order to obtain feedback on the topics and the process of interviewing. Four interviews were conducted by an experienced clinical physiotherapist and six interviews by the author of this thesis (GB). Both interviewers had experiences of guiding body awareness exercises and had their own experiences of practicing body awareness.

In **Study III and IV** three individual open-ended interviews were carried out during the participants' rehabilitation. *The first interview* was carried out just before the start of the rehabilitation programme. In this interview, focus was on experiences of managing living with persistent pain, with special focus on attitudes and beliefs about the body, issues related to identity and sense of self as well as close relationships with others. A further focus was on thoughts about the future and personal goals in rehabilitation. The concept of acceptance was not directly focused on, but described in terms of being able to manage or to come to terms with life. *The second interview* took place half way through the rehabilitation programme and was based on the previous interview. Focus was on any changes, personal choices and challenges which the person experienced during rehabilitation. *The third interview* took place at the end of the rehabilitation programme and focused on processes of learning through rehabilitation. A typical question was: "You have recently completed the rehabilitation please tell me how it was for you?" The interviews lasted approximately 45 to 120 minutes and took place at the rehabilitation clinic in a quite environment to ensure comfort and privacy. All interviews were carried out by the author of this thesis (GB), who was not involved in the rehabilitation programme.

2.4 Phenomenological methodology

2.4.1 Empirical phenomenological psychological method (EPP-method)

In **Study I and II**, the phenomena of living with and relating to a painful body and body awareness as a resource was the topic of study. For this reason, the EPP-method described by Karlsson (1995) was considered to be appropriate. This method adheres to an experiential life-world perspective, having the potential to grasp the embodied, existential aspects in humans' lives. Although the understanding of life-world experience is subjective and might be experienced differently by different people, the overall aim of the EEP-method is to identify characteristics or constituents which make up the meaning structure of phenomena, in order to gain knowledge about that which constitutes the phenomenon in question. Results of this method provide not only "essential" general characteristics, but also shed light on the variations of lived experience, that is, the various ways in which a phenomenon can manifests itself (Karlsson & Tham, 2006). The hermeneutical approach in the EPP-method involves understanding lived experience through interpretation, referring to the hermeneutical circle which means parts has always to be understood in the light of whole (Karlsson, 1995).

In empirical research the researcher has to obtain concrete descriptions of lived experience from those who have lived through situations in which the phenomenon take place. What is sought is a description that is as faithful as possible to the actual lived experience in both data collection and data analysis. The data analysis procedure in Study I and II is described in detail in the next paragraph.

2.4.2 Interpretative phenomenological analysis (IPA) and longitudinal study approach

In **Study III and IV** a qualitative longitudinal research approach was conducted (McCoy, 2017; Murray et al., 2009; Thomson & Holland, 2003) in order to explore and describe the embodied nature of acceptance and to bring out variations in the participants' lived experience and discover changes over time. The interpretative phenomenological analysis (IPA) method was chosen for data collection and data analysis because it would be able to capture these aspects

IPA has a case study approach. It is ideographic and iterative, committed to analysing each case in turn, prior to move on to more general claims (Smith, Flowers, & Larkin, 2009). IPA is congruent with taking 'a patient-centred perspective (Finlay, 2009). Listening to the views of those participating in pain rehabilitation is particularly useful for investigating complexity and processes or novelty (Grossoehme & Lipstein, 2016; Snelgrove, Edwards, & Liossi, 2013). IPA is also useful to understand processes that can be ambiguous and emotionally laden, such as learning to

accept and live with long term pain (Smith & Osborn, 2015). Normally, a small carefully selected sample is suitable for exploring what an experience, a process or a relationship means to an individual in a specific context. In this thesis IPA was used for cross-case analysis (Study III and IV) and a trajectory analysis, i.e. change over time (Study IV).

2.5 Data analysis

In **Study I and II,** the analysis steps were similar in both studies and therefore are presented here together. According to the EPP-method (Karlsson, 1995) the following procedures were performed: *First,* the interviews were read over and over again with the purpose of becoming familiar with the material as a whole in order to gain an emphatic understanding. *Second,* the material was divided into smaller units, so called "meaning units" according to the shift in meaning found in the text. *Third,* each meaning unit was examined in relation to the whole text, in relation to the phenomenon under study, in order to trace out and interpret the implicit as well as explicit meaning found in the descriptions of the participants. This process is an example of the phenomenological reduction, i.e. the researcher moved from the specific to the meaning of the specific. During this step efforts were made to "bracket" conceptualizations and theoretical understandings, prejudices and beliefs as well as personal experiences, ensuring openness to the meaning of the experiences as they present themselves. *Fourth,* this step involved synthesizing the meanings into a "situated meaning structure" for each participant. Each synthesis or synopsis illustrated what it means to be a person in pain (Study I) and how body awareness is lived/experienced as a resource (study II). In this step, the variations of the phenomenon under study became obvious and constituents were identified. *In the fifth step*, constituents were synthesized in an overall meaning structure or theme running through all interviews (Study II) and the variations of the phenomenon presented as typologies. (Study I and II).

To ensure validity i.e. to remain close to the original data in the last step, it was important to go back and forth to check interpretation and descriptions with the original material. During the analysis, the different steps performed by all the authors were subject to discussion, in order to hold the researchers pre-understanding "deliberately at bay". Pre-understandings were scrutinized and challenged by the research group. While analysis advanced, all authors discussed emerging findings with special emphasis to truthfulness to the descriptions. The interpretative process in the analysis deepened through these reflective dialogues within the research group as well as through presenting the findings in several research groups and at national and international professional conferences (Finlay, 2013; Karlsson & Tham, 2006).

In **Study III,** the interviews from time one, i.e. when entering the rehabilitation programme, were analysed according to the IPA method, using a step-by-step process, outlined as a set of flexible guidelines (Smith et al., 2009). *Step one* started with interpretative readings of the first case transcript, noting comments on everything that seemed significant. The comments were descriptive (exploring the use of language, pauses, repetition etcetera) and conceptual. The *second step* involved noting emerging themes and short statements in relation to each theme. In the *third step* the emerging themes and the short statements were examined and analysed in order to cluster them into higher-order statements. The statements included experience of the persistency of pain in relation to bodily experience, to the sense of self and to significant others. These statements were then explored in the light of how they related to acceptance as a means of finding a new way to live with long-term pain. A brief illustrative outline of each case was established. This process was repeated for each case, the vertical path of the analysis. In *the last step*, these outlines of each case were analysed horizontally looking for over-arching themes and patterns so as to establish general meaning, or qualitatively different meaning structures of the phenomenon acceptance. Three qualitatively different meaning structure of acceptance could be described.

In **Study IV**, the whole data set comprising 27 interviews were analysed according to the IPA's ideographical principles (Smith et al., 2009), taking into account the longitudinal approach (Grossoehme & Lipstein, 2016; Snelgrove, 2014). The interviews were analysed in a sequential manner, one interview at a time, before proceeding to the longitudinal comparison, and finally, searching for clusters or patterns on a group level.

At first, a cross-sectional case analysis was conducted based on the three meaning structures found in study III, with special focus on the second and third interview. We realized that we did not only get data over time, but increasingly nuanced descriptions and in-depth reflections on what it actually meant for the participants to live with long-term pain, as well as clarifications of their understandings of acceptance. Further, it became evident that some participants changed their understandings of acceptance profoundly during the time span, while others held either a stable or back and forth understanding that revealed no process of change at all. So, we decided to step back and set aside the previously described meaning structures as a point of departure for this study. *In the next phase* focus was on to deepen our understanding of the variation of the meanings of acceptance across the whole data set. The three interviews from each participant were utilized as a longitudinal unit and cross-analysed on a horizontal level focusing on patterns and structural differences. In this process four different meaning structures emerged and were described in detail and visualized with quotes from the participants.

In the last phase the interviews were re- read and analysed, utilizing a longitudinal analysis approach. Framing questions were used to hold the focus, such as; "What increases/decreases during rehabilitation", "What does the learning process look like during rehabilitation?", "Are there any typical triggers of change or new meaning perspectives?" Attention was also directed to the language used by the participants, noting descriptions of "from-to" trajectories and temporal changes such as "before and now". Finally an overall theme summarizing the learning during rehabilitation and key aspects of the process of change during rehabilitation was constructed, which described four meaning structures. When no process toward acceptance was found, the transcripts were re-read in order to highlight and describe resistance or avoidance strategies used to refuse acceptance.

2.6 Ethical considerations

To study patients raises ethical questions, especially if the focus is on bodily-existential experiences. Patients with long-term pain might be particularly vulnerable, as their condition affects many aspects of life. They suffer not only from bodily restrictions but also from a loss of identity, where one can feel alienated from the body and detached from oneself and others. Further many patients feel stigmatized due to the invisibility of the pain and left on their own to find a way to manage living with long-term pain.

Participating in interviews takes time and it can stir up emotions. This applies to all the studies in this thesis. Further, participants may wonder whether their participation in the study will influence their encounters with health professionals and thus their ongoing rehabilitation, especially the participants in study III and IV. Concerns about how the content of the interviews are handled are common. It is the researcher's responsibility to see that each participant feels comfortable and safe, and that ethical principles for conducting medical research (Beauchamp & Childress, 2009) are followed such as autonomy, informed consent, confidential treatment of data and carefully considerations of predictable risks and foreseeable benefits for the subjects. All studies in this thesis were approved by ethical committees.

For study I ethical approval was obtained by the Regional Ethics Committee for Medical Research at the Health University, Linköping (Registration No: 01-349). For study II ethical approval was obtained from the Regional Ethical Board in Stockholm (Registration No: 2010/618-31/5). For study III and IV ethical approval was obtained from the Regional Ethical Board in Stockholm (Registration No: 2010/138-31/1).

All participants received oral and written information about the study. Those who were interested signed an informed consent to participate. Voluntary participation was ensured, including the right to withdraw without any consequences. All participants were ensured anonymity when presenting the results from the studies. Quotations that would risk identifying the participants have been modified. The interviews were open-ended, which gave an opportunity for the participants to steer the course of the conversation and to choose what to talk about. Further, great effort was made by the interviewer to create an open and collaborative approach during the interviews and to be sensitive to each participant's needs during the interviews. All interviewers in the four studies included in this thesis were experienced physiotherapists. All participants had on-going contact within health care, either with a physiotherapist or a rehabilitation team. The participants were encouraged to take contact either with their physiotherapist or the rehabilitation team if they felt that they needed to talk about matters that had been brought up during interviews. Throughout the studies, the interviewer's genuine interest in what the participants had to say in the interviews encouraged an affirmative dialogue which was often experienced as beneficial to the person being interviewed.

3 RESULTS

Table 3 shows an overview of the main findings in study I–IV. For more detailed results of each study, see paper I–IV in the appendix.

3.1 Study I

The results describe how different aspects of body experience showed themselves in relation to the body as an aspect of identity, to body awareness and body reliance and ways of understanding pain during their treatment in physiotherapy due to long-term pain;

- **The body as an aspect of identity** – various degree of integration
- **Body awareness** – the quality of the perceptual flow from the body
- **Body reliance** – degrees of trust and ability to cooperate with one's body and put up with its unpredictability, having it or missing it
- **Ways of understanding pain** – the subjects own descriptions of why he/she has got and still has the pain

These aspects differed significantly in the participants' accounts. Based on these bodily aspects, four typologies reflecting different ways of relating to the body and thus to the persistency of pain were uncovered. The typologies have been named: '*Surrendering to one's fate', 'Accepting by an active process of change', 'Balancing between hope and resignation'* and *'Rejecting the body'*.

Acceptance was found to be an overarching theme, whether or not it is achieved, and how it is achieved. Participants gave different accounts as to how they related to acceptance, reflected in the degree to which the aching body could be integrated into their sense of self. This was facilitated by a basic trust in one's body, one's degree of body awareness and the understanding of one's pain. Body awareness had to do with the degree in which one had contact with and could listen to bodily signals in order to adjust to it, while body reliance meant if and to what degree one could trust and cooperate with one's body, despite pain and unpredictability of the body.

'Surrendering to one's fate' means one has accepted living with the aching body and the persistency of pain, taking on an attitude that life is a matter of adaption. "Yes … you have to alter your life pretty much". One is aware of the limits of the body and listening to bodily signals becomes quite natural in everyday life. It is described as feeling 'at home'. One has realized that the pain does not disappear, so why fight against it? "Yes, it hurts, … and the body is tired, you know, but my back hurts a lot… and it is lovely to sleep for a while, really to stretch oneself out and just lie down."

Table 3. Overview of the main findings in study I–IV

Project	**Experiences of the body in pain**	**Experiences of body awareness as a resource**	**Experiences of the meaning and the process of acceptance during rehabilitation**	
Study	**I**	**II**	**III**	**IV**
Research question	How do individuals with long-term pain experience and relate to their aching body?	How do individuals with long-term pain experience body awareness as a resource in their rehabilitation?	How do individuals experience and understand acceptance when entering a pain rehabilitation programme?	How do individuals experience and understand acceptance and the processes of change during a pain rehabilitation programme?
Setting (n)	Participation in physiotherapy in primary care or specialist pain care (n=20)	Participation in body awareness therapy in primary care or specialist pain care (n=10)	Attending a 16 week-long pain rehabilitation programme in specialist pain care (n=9)	
Main results	Various aspects of body experience such as the body in relation to identity, body awareness and body reliance, as well as various models of explaining pain among participants. Based on these aspects four typologies forming a spectrum were identified; *(I) Surrendering to one's fate,* *(II) Accepting by an active process of change,* *(III) Balancing between hope resignation,* *(IV) Rejecting the body.* Patients with long-term pain can be found along a spectrum from accepting till rejecting the body. Body awareness and trusting one's body seem to be important for the path towards acceptance.	Three constituents were identified as central to a gradual 'moving forward process', emphasizing the essential meaning of body awareness as a resource; *(I) Directing attention towards bodily sensations with a new intention,* *(II) Broadening the perspective and directing attention to-wards personal agency,* and *(III) Redirecting attention towards the outer world by trusting the body*. Each typology presents a shift in attentional focus and illustrates different challenges which need support at the right level in order to facilitate body awareness as resource.	Three meaning structures were identified; *(I) Acceptance as a personal empowerment process, 'the only way forward',* *(II) Acceptance as an equivocal project, 'a possible but challenging way forward',* *(III) Acceptance as a threat and a personal failure, 'no way forward.* Patients with long-term pain can have different understandings of acceptance when starting rehabilitation. Bodily-existential challenges are related to the different meanings held by the participants. An embodied learning process is hypothesized as facilitating a path towards acceptance.	Four meaning structures that deepened the understanding of acceptance as well as illustrating key aspects of an ongoing learning process during rehabilitation were identified; (*I) Acceptance as liberation,* *(II) Acceptance as acknowledging the need for change,* *(III) Acceptance as tolerating ambivalence,* *(IV) Acceptance as failure.* Two fundamentally different possibilities emerged. On the one hand, attending a rehabilitation programme facilitated an embodied transformative learning process which leads towards acceptance. On the other hand, attending a rehabilitation programme might further reinforce resistance and thus prevent any steps towards acceptance.

'Accepting by an active process of change' means one has accepted having to make active choices in everyday life in order to be able to live a meaningful life. Here there is a trusting cooperation between self and body, a trust that the body, despite pain, will be helpful in navigating in life. The body is looked upon as a speaking partner and teacher. A bodily anchored acceptance is clearly expressed. "The body is me and I am very grateful today that it is wiser than me".

'Balancing between hope and resignation' means one struggles with ambivalence. Accepting that the troublesome body may be a part of one's future is experienced as necessary but challenging, especially trying to integrate the aching body into one's sense of self. One's relationship to the body is ambiguous and moves between listening to the body and shutting it off. "It (the body) does not make it. And then I have to think things over again. But it is hard, yes it is …", "I don't take much notice of the pain. I don't know if I've gotten used to it… oh my God … I have pain everywhere."

'*Rejecting the body'* means one is not in control of the body, which makes life difficult and unsafe. The body is separated from the self and impossible to understand. Change is not achievable and integrating the aching body into one's sense of self is impossible. The body is an enemy and life itself is experienced as a prison "No, no, no, I won't do it. No, I don't know how my body will react in different situations… it is against me."

The results indicate that acceptance for patients with long-term pain showed itself along a spectrum from accepting to rejecting the aching body and the life situation as a whole. However this spectrum does not necessarily manifest as a straightforward process from rejecting to acceptance but rather as a process from crisis to equilibrium. Furthermore, body awareness and trusting one's body seemed to be central, not only for accepting the aching body but also to be able to manage the life situation as a whole, which is an important finding for further research.

3.2 Study II

Body awareness treatment approaches are commonly incorporated in pain rehabilitation and positive outcomes have been reported. However, we do not know specifically how enhanced body awareness is experienced and if or how it contributes to processes of change in rehabilitation. This is especially important as difficulties in attending to bodily experiences are common among individuals who feel disconnected or alienated from the body due to long-term pain.

The results in study II describe an embodied 'moving forward' process, experienced as body awareness as a resource in the participants rehabilitation and thus in their everyday life. This gradual 'moving forward' is characterized by a shift in

attentional focus that concerns the lived body, the embodied sense of self and the life-world beyond the experience of pain. During this process there is hope that one day one may regain ones' life, which is understood as the opposite of experiencing 'living a life on hold'. Three constituents were found to be central in this moving forward process; (*I) Directing attention towards bodily sensations with new intention, (II) Directing attention towards personal agency, (III) Directing attention towards the outer world by trusting the body.*

(I) Directing attention towards bodily sensations with new intention. This means one has to open oneself up to a new way of listening to the body and be able to adopt an attitude of curiosity. Ultimately, it is about practicing a perceptual openness to the lived body, a process that requires courage, as opening oneself up to something new could be experienced as painful. This new way of perceiving is often experienced as time-consuming hard work and challenging in several ways. The physiotherapist must provide a sense of safety by creating a safe therapeutic space, which includes a person-centred approach.

(II) Directing attention towards personal agency. Enhanced contact with the body enables the person to explore how they can affect their own body, but also allows them to notice how the body reacts to what happens in life, as opposed to experiencing that the body lives a life of its own. It further enables the person to explore different ways of acting towards not only the body, but also towards oneself as well as significant others. This strengthened sense of agency is a critical feature of this shift in perceptual openness towards the embodied self, as it implies responsibility. It also provides a sense of hope. Living life becomes easier. However, openness towards the lived body also highlights the split between the body in pain and one's sense of self. Noticing this split could be experienced as an awakening, although it could also be an experience filled with feeling guilt and self-blame. In order to embark on this inner journey, support is needed to facilitate an accepting and compassionate attitude towards oneself and support in finding new ways of relating to the body-mind unity.

(III) Directing attention towards the outer world by trusting the body. Once it is possible to rely on one's ability to listen to the body and respond accordingly, it will pave the way for a basic sense of trust in the body. This enables the body to once again slide into the background. The body can be experienced as a safe base, from which one can project oneself beyond here-and now experiences towards the future. It becomes possible to engage in life, beyond dealing with pain. Pain is still present, but the impact on the person's life has decreased; it has lost its grip on the body and the person, which means that pain no longer needs to be avoided. Instead the person takes charge, making it possible to start living again.

The results suggest that perceptual openness and the pleasure of discovery are important parts in the embodied learning process of pain management. This is also important in order to discover a new intention when directing attention towards the body. Body awareness challenges and enhances embodied trust and can foster a forward-looking process, thus constituting a bridge between the past, the present and the future. This looking-forward process is in line with the overall aim of pain rehabilitation, which is to restore function in everyday life. However, patients in pain rehabilitation may experience various challenges on their path towards experiencing body awareness as a resource. Support and guidance at the right level at the right time is needed. An overview of the three constituents understood as therapeutic processes and related themes are presented in Table 4.

Table 4. Constituents and related themes reflecting body awareness as a resource

I	**Directing attention towards bodily sensation with a new intention – perceptual openness towards the lived body**
	Giving oneself space to calm down – becoming engaged in bodily experience Becoming curious and open-minded – making new discoveries about bodily sensations Appraising/reappraising bodily sensations – unfolding a compassionate attitude to oneself
II	**Directing attention towards personal agency – perceptual openness towards the embodied self**
	Exploring new ways of acting towards oneself Exploring new ways of acting towards others
III	**Directing attention towards trusting the body – perceptual openness towards the life-world**
	Trusting the body – letting go of control Balancing attentional focus – becoming more spontaneous

3.3 Study III

Learning to live with and manage long-term pain requires that one has to accept the persistency of pain and one's life situation as a whole. This is a challenging task and seems to be a personal and individualized process. Entering a pain rehabilitation programme brings this task to the foreground, although it is not always targeted in a conscious manner by the health professionals. In order to understand the point of departure for each patient when starting their rehabilitation, we need to understand the lived experience of acceptance, especially in relation to bodily-existential challenges, as emphasized in study I.

In study III, three different meaning structures emerged; *(I) Acceptance as a personal empowerment process, "the only way forward, (II) Acceptance as an equivocal project, "a possible but challenging way forward", (III) Acceptance as a threat and a personal failure, "no way forward".*

The different meanings of acceptance were related to if one was able to give up the struggle with pain and accept that pain probably will remain, at least for a long time, so it is better to learn to live with it. Acceptance also concerned accepting that the body and self will not be experienced as before, and that help from others is needed. Thus, it is important to address bodily existential aspects in rehabilitation, such as how one relates to the lived body and the need for changes in core aspects of self, and to accept help from significant others as well as helping others to help oneself. It becomes also obvious that acceptance is more than learning to live with and coming to terms with one's condition or managing pain, it is about getting back on track and 'moving on' with a meaningful life. It is also about accepting change. Thus the overall motive for entering the path towards acceptance was ultimately related to the longing for 'moving on with life', opposed to the experience of a living a "life on hold", being controlled or stuck in pain.

Table 5 presents an overview of the characteristics of each meaning structure in relation to the differences in the overall attitude to living with long-term pain, the relationship to the body in pain and one's sense of self and significant others.

Table 5. Characteristics of the three meanings of acceptance

Acceptance as a personal empowerment process, "the only way forward"
"*I can be in charge and I can make a difference"* (pain is understandable and possible to affect)
"I can do everyday activities – but in a different way" (the body as a resource and important guide)
"*I can manage it and I'm still the same person"* (I'm proud to manage it)
"I can manage it with support from others" (acknowledging the need for support from others)
Acceptance as an equivocal and uncertain project, "a possible but challenging way forward"
"*How can I understand pain – Is there a pattern?"*
"How can I relate to the ambiguous and lived body?"
"How can I trust my own ability and manage uncertainty and responsibility?"
"How can I communicate and socialize with significant others?"
Acceptance as a threat and a personal failure, "no way forward"
"*The pain sends me out of control and without responsibility"*
"*The pain makes me feel entrapped and disappointed with my body"* (The body is no longer me)
"The pain makes me be who I am" (I'm a person in pain)
"The pain makes me feel shame and guilt towards significant others"

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The results indicate that patients can hold different understandings of acceptance when entering a pain rehabilitation programme and are as such engaged in different bodily-existential challenges on their path towards acceptance. Acceptance could be experienced as a threat and an indication of personal weakness, which makes any change impossible. The body can be experienced as a resource and source of enjoyment but at the same time a hindrance. Bodily experiences are an important part of the process of acceptance, as they can be experienced as challenging and, if not recognized, acknowledged and worked through, they might constitute an obstacle to moving forward in rehabilitation. An embodied learning process is proposed as a way to help patients achieve acceptance.

3.4 Study IV

The aim of the study was to explore how participation in a rehabilitation program influences the meaning given to acceptance. During the serial interviews the participants gave rich descriptions of what acceptance meant to them, and how these experiences changed over time. Four distinct ways of experiencing acceptance were identified;

(I) Acceptance as liberation, (II) Acceptance as acknowledging the need for change, (III) Acceptance as tolerating ambivalence; (IV) Acceptance as failure. Related to these four meanings of acceptance different aspects of an ongoing embodied learning during rehabilitation were highlighted. Characteristics of each meaning of acceptance are described in detail in the manuscript – paper IV.

In *'Acceptance as liberation'* an embodied transformative process of learning is the prominent feature, where the conflict of who is charge – is it me or is it the pain - is solved. A cooperative relationship between the body and the self exists, which enables a shift in focus from pain and pain management to self and self-management. There is also a significant shift in focus regarding one's relation towards the body and significant others.

In '*Acceptance as acknowledging the need for change'* the focus is on actively regaining a sense of control instead of being a victim of pain. Putting oneself first and becoming knowledgeable about pain, together with the discovery that one can make a difference facilitates a sense of personal agency and thus constitutes a move forward on the path towards acceptance.

In *'Acceptance as tolerating ambivalence'* the focus is on the here and now, this very second, in emotional reactions to pain and finding a way to handle the struggles involved in living a life with pain. The movement toward acceptance includes learning to differentiate and regulate bodily experiences and acknowledging emotional reactions as reasonable response. One is aware that the body can be both a source of living a meaningful life as well as a hindrance to living a meaningful life.

In *'Acceptance as failure'* the focus is on the past, on how things use to be, before the pain. Effort is placed upon resisting any movement towards acceptance, as this would mean surrendering in the battle against pain and admitting that one will not get better. It was found that an uncertainty of the overall goal of rehabilitation and one's own role and responsibility could fuel resistance to any process of change.

To summarize the results of the four studies, two fundamentally different possibilities emerged for persons going through a rehabilitation program. On the one hand, attending a rehabilitation programme facilitated an embodied transformative learning process and enabled persons to move towards acceptance, although they approached acceptance in different ways. On the other hand, attending a rehabilitation programme in some cases reinforced resistance strategies and thus prevented any steps being taken towards acceptance.

The results indicate that patients can hold different understandings of acceptance when attending a pain rehabilitation programme; from actively rejecting the idea of acceptance, to actively taking steps towards acceptance. They may understand acceptance as failure, approach it with ambivalence, or acknowledge that change is needed, experiencing it as liberation.

Each path towards acceptance poses different challenges. Rehabilitation professionals need to be aware of and sensitive to the different understanding of acceptance and be attentive to the fact that these different understanding require different forms of support during rehabilitation.

4 DISCUSSION

The studies in this thesis have pointed out the importance of acceptance as an integral part of the process of moving forward from a pain-focused life towards a meaningful life, despite pain; from being disconnected from the body to celebrating bodily experiences, from social withdrawal to communication and connectedness. Furthermore, the experience of the body in the learning process was found to be important for those who managed to make progress in their rehabilitation.

4.1 Acceptance as integral to the process of moving forward

To move forward can be referred to as an experience of being on the move, as a journey towards living a meaningful life despite pain, as opposed to living a "life on hold". Experiencing a life on hold as well as feeling stuck in pain is highly challenging experiences from an existential point of view (Bunzli et al., 2013). In this sense acceptance is more than coming to terms, its more about getting back on track and move on with the business of living life, about active change and making choices.

The role of acceptance in this process of moving forward was found to be important in all the studies in this thesis, either explicitly or implicitly. Even in the first two studies, which did not explicitly focus upon acceptance, the participants touched upon acceptance in various ways. It was also found that this moving forward gives rise to hope, when acceptance opens up possibilities to a new meaningful life, despite pain. Acceptance is about giving up the struggle searching after cure and pain relieve and thus finding a new way to having hope. Acceptance means a shift in focus i.e. there is no longer focus on losses, but on redefining and reconstruction.

Moving forward also involves challenges e.g. letting go and leaving behind an identity based upon being pain free and being able to embrace the idea of a new or partial new identity involving living with a body in pain and limitations and an altered life-world. This has also been described by Asbring (2001). The role of acceptance in this moving forward is different depending upon the meaning of acceptance as articulated in the different meaning structures found in Study IV. In "liberation" acceptance is a self-evident part of life and helps one to develop into a new identity. In "acknowledging change", acceptance helps one to take responsibility and control over the pain instead of being a victim of pain. In "tolerating ambivalence" one does not entirely embrace acceptance, because one is caught up in frustration and emotional reactions towards pain. In the last typology, "failure" acceptance is not anything positive and as such not worth striving towards, so they cannot engage in working towards a new identity.

Toye et al. (2013) has described in a systematic review that some people could experience living with long-term pain as moving forward alongside with pain. This process of moving forward in relation to acceptance has also been shown in a study investigating the experience of how to achieve acceptance of pain for people with spinal cord injury (Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2012). In this study, acceptance is described as the final goal of rehabilitation, consisting of different steps. However, the concept of acceptance is not nuanced as in our studies. It has also been described by Kostova et al. (2014), who investigated the process of acceptance in people with rheumatoid arthritis. Both studies described a similar process on how to achieve acceptance, with a final step including the integration of the pain into one's life.

In this thesis we found that it was important to integrate pain into ones' life. The integration of the painful body into one' sense of self appears as important in our studies. Moving forward integrates both self, body and others

4.2 Acceptance in relation to reconstruction of self

The importance of identity redefinition in connection with long-term illness and disease is illustrated by Bury's notion (Bury, 1991) of "biographical disruption", a well-known concept in sociology, describing how chronic illness disrupts structures of everyday life. Not only daily routines and habitual ways of being, thinking and acting are altered but also a coherent sense of self. It is a highly distressing experience giving rise to a sense of uncertainty. Literature has shown that identity crises and the need for self-redefinition and life restructuring have been reported for persons with long-term pain in order to adopt and adjust (Corbett, Foster, & Ong, 2007; Osborn & Smith, 2006; Toye & Barker, 2010). Acceptance of the need for new self-definition does not imply resignation but could be understood as psychological flexibility, becoming engaged in meaningful activities, both in present and the future.

The studies in this thesis have shown the different challenges along the way towards regaining a meaningful life, despite pain. Bunzli et al (2013) emphasized that these challenges could be related to a suspended biography, which includes suspended wellness, suspended self, and a suspended future. Persons living with long-term pain put wellness "on-hold" until they feel that they have gotten legitimacy for their suffering. Suspended self means emotional distress such as anxiety, depression, anger and frustration amount to a sense of "not being me" when experiencing pain. Suspended future means one faces uncertainty, which includes a day-to- day battle to control pain, and a "wait and see" attitude towards future plans. One feel trapped in the battle for legitimacy, the hope to regain the pre-pain self and identity as well as the day-to day struggle to control pain. These experiences block

the movement towards a future self, leading to a sense of entrapment "Who I am and what choice do I have" (Morley, Davies, & Barton, 2005). Smith and Osborn (2007) show how pain is an assault on a person's sense of self and identity.

In this thesis, reconstructing the sense of self has been found to be challenging, but necessary. Bullington et al (2003) has described how disorienting long-term pain can be for the person, describing it as a disorienting chaos. Ordering chaos, for persons with long-term pain, had to do with identity and responsibility, which came about when persons had achieved a sustained feeling of control and mastery over their situation. The meaning of their suffering could be articulated together with the health care worker and had ultimately to do with the persons' sense of self.

4.3 Embodied transformative learning

The idea of transformative learning comes from the work of Mezirow (1991,1994). Central to this theory of learning is the importance of being able to shift perspective and transform meaning constitution. Transformation in this theory refers to the way in which persons change their perceptions and ideas in order to achieve new skills and ways of acting, feeling and thinking. Mezirow describes the process of transformative learning in three dimension, the psychological, convictional (belief systems) and behavioural. Often, transformative learning results from a disorientation or life crisis, which brings about the process of change. Key factors in this theory are the role of reflection and the ability to take a meta-perspective.

This way of approaching learning is relevant for health and rehabilitation in order to understand processes of change. Various models have been developing based upon this approach to learning within rehabilitation. One such model is found in the work of Dubouloz (Dubouloz et al., 2010; Dubouloz, Laporte, Hall, Ashe, & Smith, 2004) and colleagues (King, Klinovski, & Dubouloz, 2016). This model provides insight regarding the complexity of patients' experiences of learning to live with long-term health conditions. The focus here is more on the process of change during rehabilitation rather than outcomes. The movement from ill health to health has to do with the deconstruction and reconstruction of the meaning of pain, body, other etc. Ashe, Taylor and Dubouloz (2005) has used transformative learning theory in arthritis education groups in order to develop and understand meaningful group experiences in the process of change leading to desired health outcomes. This was in line with the embodied learning experiences of a physiotherapy group treatment for patients with fibromyalgia (Mannerkorpi & Gard, 2003).

4.4 Re-integration of body and mind in the rehab process of long-term pain

The studies in this thesis have shown that persons who suffer from long-term pain often experience a split between themselves and their body. This has also been demonstrated in other studies (Crowe et al., 2010; Osborn & Smith, 2006; Snelgrove & Liossi, 2013). Being able to once again experience the body and mind unity projected towards the world (instead of fixating on the painful body) was a salient result in all the studies in the thesis, especially in study II. The participants were often engaged in a battle with the body for control. The process of re-integrating oneself with ones' body showed itself to be a gradual and stepwise development. The beginning of the process was to be in a battle with the body. A struggle for control (who is in charge) as well as hypervigilance attention to the body was the common experience, which inhibited engagement with the world. When individuals were able to listen to their bodies in a calm, reflective and compassionate way, it opened up for an acceptance of the body as being a part of themselves. The next step was to understand the patterns of body experiences, and then be able to explore (nuance and differentiate) different experiences of the body. When this could be experienced without being overwhelmed, a trust in the body began to return. They discovered in daily life that they could in fact influence and manage their bodies and their pain. This enabled them to reclaim the body-mind unity and ultimately be able to celebrate body experience, even in the presence of pain.

The importance of breaking the fixation on the painful body is well known within physiotherapy using body-mind techniques e.g. BBAT (Ekerholt & Bergland, 2019; Gyllensten et al., 2010) However, it is not always self-evident in the case of rehabilitation of persons with long-term pain. It is our hope that this thesis illustrates the importance of this re-integration for regaining health. The different steps in this process, described above, can be an inspiration for health care workers, specifically physiotherapists, in their treatment of these patients.

The notion of transformation is in line with Bullington (2009) who, based upon the philosophy of Merleau-Ponty (1945/1962, 1964/1968) described the goal in rehabilitation in terms of structure transformation of habitual ways of thinking, feeling, acting and belonging to the world. Pain calls for a transformation of the lived body, in terms of mind-body and world unity, together with the concurrent transformation of the field of experience.

4.5 Body awareness as a resource for health

The results of the studies in this thesis have shown that it is not a bad idea to encourage body awareness for these patients, even if the process can be challenging for persons suffering from long-term pain. Becoming aware of ones' body in a new way not only results in less pain (for some) and better function, but also provides a positive experience of broadening ones' horizon through learning. The benefits include feelings of pride and freedom as one is able to live life despite the pain.

Body awareness training and the ability to practicing it in daily life, consists of being able to shift focus in how one pays attention to the body. One learns to be open and curious about the body rather than continuously checking and searching for negative. They are no longer steered by negative sensations. This enhances the feeling of being in charge and moving on. They body is no longer an enemy, but a part of the person. The ability to pay attention to the body and discover new aspects of ones' body and ones' ability leads to a feeling of agency rather than passivity. The result of body awareness in ones' life is that one is free to trust in the body and engage in the world in a spontaneous way.

Gyllensten et al (2010) found that training body awareness strengthens both agency and body identity. Other studies have found that regaining contact with one's body seems to be a predicting factor for positive rehabilitation outcomes Gustafsson et al., 2004; Löfgren Ekholm, & Öhman, 2006; Van det Maas et al., 20015; Van der Maas et al., 2016). Gustafsson et al (2004) found that developing body awareness and bodily knowledge during a rehabilitation programme started a positive process of change, moving specifically from shame to respect. In another study it was shown that individuals with fibromyalgia who stayed at work despite pain had become experts in body awareness and were able to their own bodily needs in a new way. For example, they utilized increased awareness of the body signals in "pain as a guide" strategy in order to prevent increased pain or deterioration (Lofgren et al., 2006).

Danielsson and Rosberg (2015) investigated experiences of BBAT with patients with major depression. They found that body awareness made the persons more open and full of vitality, despite depression. This shows the same result as in our study II, that is, persons can live with pain while simultaneously living meaningful lives. A physiotherapist has developed and tested a key questionnaire to support dialogue with patients about bodily-existential challenges. She found that the dialogue started a process of change and it is possible to discuss these types of issues with patients, but physiotherapists need support in order to take up such topics. This was a matter of uncertainly about the professional role or mandate of physioterapist (Afrell & Rudebeck, 2010).

4.6 Methodological considerations

The phenomenological framework was the theoretical perspective used in order to interpret the data, as the research topic concerned a comprehensive exploration of experiences and understandings.

Two different phenomenological methods were chosen, according to the different aims and study design. IPA is a well-known qualitative method used to explore lived experiences, found to be especially valuable for the cross-sectional approach of longitudinal data (Smith, Flowers, & Larkin, 2011). The EPP-method (Karlsson, 1995), combined both phenomenological and hermeneutical steps in the method so as to be able to grasp essences, structures and characteristics of the studied phenomenon. Some challenges were involved with these choices. They were both sophisticated methods based on phenomenology, requiring mastering both phenomenology as well as the methodology involved. A further challenge was the extensive amount of written material, due to the serial interviews conducted during rehabilitation (study IV). However, working in close cooperating within the research team was important and helpful to maintain focus.

An interpretative approach was required in order to fully understand the participants' experience of living with long-term pain, and investigate how they make sense of these experiences. "Lived experience" refers to the way in which one formulates meaning in relation to one's situation, one's experiential life-world. Thoughts, emotions and actions are all expressions of lived experience Carel, 2011; Finlay, 2009).

Interpretation of the data has to be grounded in concrete experiences of the participants. The stepwise analysis approach found in both IPA and the EPP-method was a helpful strategy as well as close collaboration within the research team. However, as in all phenomenological research, the subjectivity of the researcher has to be bridled or "put into brackets". Pre-understandings and assumptions about long-term pain as well as how to achieve body awareness or acceptance were thoroughly reflected upon at the start of each study.

Selection of participants has to be carefully considered in qualitative studies. In study II, physiotherapists recruited participants who were interested in discussing and reflecting on bodily experiences. This could be understood as limitation in terms of transferability, but it was a prerequisite in order to get rich and thick descriptions of body awareness as resource. In study III and IV, the heterogeneity in the sample supported both validity and transferability of findings. We imagine that the study sample was probably not different from any group of patients usually referred to pain rehabilitation clinics. However, we cannot claim that our findings are transferable to individuals in other contexts.

In study III and IV nine participants were interviewed three times during the rehabilitation period. The purpose was to investigate both breadth and depth of their experiences. In retrospect, this was an unusually large sample, carrying a risk of being overwhelmed in the analysis. However, we found that the longitudinal approach was the greatest strength of study IV. All participants generously shared their lived experience, which were further reflected upon and deepened in the subsequent interviews. Repeated contact between the interviewer and the participants generated increasing closeness, allowing access to private and sensitive issues. However, closeness presented some challenges to the interviewer. Emotional responses such as sympathy or antipathy, as well as tentative theoretical interpretations risked influencing the subsequent interviews. The interviewer maintained a recurrent check on these attitudes, trying to manage emotionality and to be open towards the participants' narratives.

An open and discovering attitude, a willingness to listen, see and understand was important in both the interview phase and the analysis phase (Finlay, 2013). The interviewer had to be sensitive enough to make visible the meanings embedded in the participants' the rich and thick descriptions of the lived experiences. The aim of the analysis was to discover and articulate implicit meanings rather than merely repeating the participants' descriptions of lived experience. The process of understanding participants' accounts (and silence) is about opening up for meanings:

"To understand a phrase is nothing else than to fully welcome it in its sonorous being ... to hear what it says .... The meaning is not on the phrase like the butter on the bread, like a second layer of "psychic reality" spread over the sound: it is the totality of what is said ... it is given with the words for those who have ears to hear" (Merleau-Ponty, 1964/1968 p. 155).

5 CONCLUSIONS

In pain rehabilitation it is important to be aware of the complexity of long-term pain. This thesis has shown both the importance of acceptance for rehabilitation as well as the role of embodied transformative learning. Acceptance was found to be a multifaceted phenomenon varying from person to person and over time. Although body awareness approaches are prevalent in some clinical settings, these studies show from an experiential perspective that body awareness has an important role to play in the successful rehabilitation of long-term pain. The findings in this thesis support the person-centred approach in rehabilitation, weather in group or individual treatment.

6 CLINICAL IMPLICATIONS

Health care professionals and fellow patients in the pain rehabilitation group have an important impact on challenging ones perspective on pain.

Health care professionals have to be sensitive to and have knowledge about how individuals experience both pain and the process of acceptance, which has been shown to be integral to the rehabilitation process. They need to know how to encourage embodied transformative learning as well as avoiding interfering with the patients' own process. They must also be able to work with a person-centered approach within the rehabilitation group. A deeper knowledge of patients' point of view can potentially make health care for these patients much better.

The results of the studies have given valuable knowledge about how to offer a person-centred approach in pain rehabilitation practice. The bodily existential challenges presented in the thesis, for example the need to develop an integrated relationship with the painful body, can inspire health professionals to develop interventions and communication strategies focusing on the lived body. A wide range of competencies in rehabilitation clinics seems to be needed.

7 SUGGESTIONS FOR FURTHER RESEARCH

Because the phenomenon of acceptance has been shown to be complex and varies over time, it would be of great value to investigate how health care professionals in pain rehabilitation understand acceptance and how acceptance is addressed in pain rehabilitation programmes.

Feeling legitimized in ones' suffering and being encouraged by health care professionals, family members and friends as well as fellow patients in the rehabilitation group were highlighted as significant for rehabilitation. Further investigation of this empowering process in pain rehabilitation practice would be important, especially in a group-based pain rehabilitation programmes.

From a physiotherapists' point of view, it would be interesting to further develop treatment strategies based on embodied learning and to be able to adapt treatment to the individuals' own personal journey towards acceptance.

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